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Online supplementary material - Survey Instrument

Article title: The impact of reproductive issues on preferences of women with relapsing multiple sclerosis for disease modifying treatments

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Welcome!

This survey is part of a study which aims to find out people's views about disease modifying treatments (DMTs) for MS. It is funded by the MS Society.

Your responses will be treated confidentially.

There are several parts to the survey and it should take about 20-30 minutes to complete.

Thank you for taking the time to complete this survey.

Information and consent

This survey is part of a study called CRIMSON: Considering risk and benefits in Multiple Sclerosis Treatment Selection. It is funded by the MS Society and is run by researchers at the University of Leeds and lead by Dr Ana Manzano.

This study helps us to understand how people with relapsing remitting multiple sclerosis make treatment choices and to develop ways of supporting healthcare staff and people with multiple sclerosis in decision-making.

You do not have to take part in this study. If you do take part, you are free to stop responding at any time. However, we may still use the responses you have given up to this point.

This survey is managed by a software research company called Accent. Your data will be encrypted and stored securely at the University of Leeds on a secure, encrypted hard drive. With your permission, we could compare your responses with other data in the MS Register.

We may use anonymised data from this survey in future research studies.

- o I understand that my participation is voluntary and I am free to stop responding at any time.
- o I understand that my responses will be kept strictly confidential. I give my permission for my responses to this survey to be compared with other responses that I have submitted to the MS Register.

- o I agree for my anonymous responses to this survey to be stored and used in future relevant research.
- o I agree to take part in this survey.

Instructions

We want to find out what sorts of things people value in disease modifying treatments. We do this by asking you to choose between two imaginary treatment options.

Each imaginary treatment option is described in terms of 6 features. These features are similar to those of currently available treatments. However, no one option represents a current type of treatment.

Next we'll show you an example which helps explain the types of questions we'll be asking you.

Example – pizza

In this example, researchers want to find out what type of pizza people like. There are three features they are interested in: size, topping and price.

To find out what people like, they are asking them to choose between two made-up pizzas, which are described in terms of size, topping and price. For example:

	Pizza A	Pizza B
Topping	Mushroom	Peppers
Size	9 inches	12 inches
Price	£4	£7
I choose:	Pizza A ☐	Pizza B ☐

People answering the survey put a tick in the last row indicating which pizza they prefer.

There is no right or wrong answer. It depends on individual taste.

Your task

Instead of choosing between pizzas, you will choose between treatments.

Here is an example question/

We will explain the features of each treatment on the next screen.

	Treatment A	Treatment B	No treatment
Average number of relapses over 4 years	1 relapse	3 relapses	4 relapses
Relapse severity	Requires oral steroids	Requires intravenous steroids	Requires intravenous steroids
Average number of people whose functioning has become significantly worse after 10 years	650 out of 1000 (65%)	750 out of 1000 (75%)	800 out of 1000 (80%)
Typical side effects of treatment	Severe - manage with MS clinic visit	Mild - No additional medication	....
Chance of additional long-term and/or life-threatening medical condition over 4 years	200 in 1000 (20%) chance of long-term condition 20 in 1000 (2%) chance of life-threatening condition	300 in 1000 (30%) chance of long-term condition 2 in 1000 (0.2%) chance of life-threatening condition	....
How you take the treatment	Two infusion (drip) treatments, 1 year apart, takes several days at a hospital	Pill taken daily, takes less than a minute at a convenient location	....
I choose:	⚪ Treatment A	⚪ Treatment B	

You make your choice between treatment A and treatment B in the last row of the table.

You should imagine that you can only choose between the two treatment options shown. No other treatments are available, including the treatment you're taking now (if any). One treatment will be better for some features and one treatment will be better for other features. You should choose the one which, on balance, you prefer.

Once you've made your choice between treatment A and treatment B, we will also ask if you would prefer it over no treatment.

We are interested in your own personal views. There are no right or wrong answers.

Before you start, here is a list of the features we use to describe treatments.

Treatment features

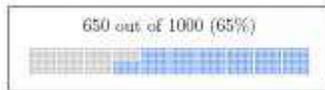1) Average number of relapses over 4 years

The average number of times people taking this treatment will have a relapse over a **4-year** period. (A relapse is a worsening of MS symptoms.)

2) Relapse severity

The **typical** steroid treatment that people on this DMT require after a relapse, depending on how severe it is. Can require either: **no** steroids, **oral** steroids or **intravenous** steroids.

3) Average number of people whose functioning is significantly worse after 10 years

Example:

650 out of 1000 (65%)

The grid of dots represents **1000** people taking the treatment and blue represents people whose functioning has become significantly **worse** after **10 years**. Worse functioning could be, for example, problems with mobility or cognition.
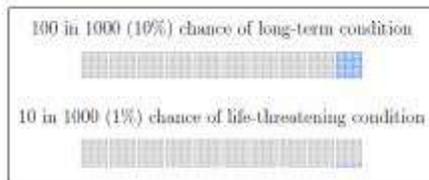
4) Side effects of treatment

How severe the **typical** side effects of treatment are, and the **most common** way people manage them. Not everyone's experience of side effects is the same, but this tells you what you can generally expect. Can be either:-

- **Mild** (manage with no **additional** medication)
- **Moderate** (manage with **over the counter medication**)
- **Severe** (manage with **MS clinic** visit)

Side effects could include flu-like symptoms, headaches, stomach pains, or similar.

5) Chance of additional long-term and/or life-threatening medical condition over 4 years

Example:

100 in 1000 (10%) chance of long-term condition

10 in 1000 (1%) chance of life-threatening condition

Each grid represents **1000** people taking the treatment.

The blue dots represent how many of those over **4 years** developed an additional **long-term medical condition.** Additional long-term conditions could include thyroid problems or liver damage.

The blue dots below represent how many over **4 years** developed a **life-threatening medical condition**.

6) How you take the treatment

How people take the treatment, how frequently, and the routines needed. Can be either:-

- Pill taken daily, takes less than a minute at a convenient location
- Self-injection every two days, takes 10-15 mins at a convenient location
- Infusion (drip) once a month, takes several hours at a hospital
- Two infusion (drip) treatments, 1 year apart, takes several days at a hospital

There are **EIGHT** questions in this section.

Part 2

We'd like to ask a few questions about yourself and your experiences with DMTs.

What is your gender?

- o Male
- o Female
- o Other
- o Prefer not to say

How many relapses have you experienced in the last 12 months?

Think about the **worst** relapse you've ever experienced. On a scale from 0 to 10, how severe do you consider it to have been? 0 = not severe at all, 10 = extremely severe.

Are you currently experiencing a relapse?

- o Yes
- o No

If yes: On a scale from 0 to 10, how severe do you consider your current relapse to be? 0 = not severe at all, 10 = extremely severe.

If no: Think about your most recent relapse. On a scale from 0 to 10, how severe do you consider you consider it to have been? 0 = not severe at all, 10 = extremely severe.

Think about your MS as a whole. On a scale from 0 to 10, how severe do you consider your MS to be when you're having a **good** day? 0 = not severe at all, 10 = extremely severe.

Think about your MS as a whole. On a scale from 0 to 10, how severe do you consider your MS to be when you're having a **bad** day? 0 = not severe at all, 10 = extremely severe.

Are you taking a disease modifying treatment?

- o Yes
- o No

If yes: Please select which disease modifying treatment you are currently taking and for approximately how long.

Have you taken any disease modifying treatments in the past which you are no longer taking?

- o Yes
- o No

If yes: Please list any disease modifying treatments you've taken in the past, and your reason for stopping. Don't worry if you can't remember all the details, just answer as best you can.

Are you or your partner thinking about having a child, either soon or in the next few years?

- o Yes
- o No

If yes: Are you and your partner currently trying to conceive?

- o Yes
- o No

Are you currently pregnant?

- o Yes
- o No

As you may know, some DMTs can affect reproduction for both men and women.

For example, some DMTs can affect the chance of having a safe pregnancy if taken during pregnancy/conception.

Would you be willing to answer 5 extra questions about disease modifying treatments and their effect on reproduction?
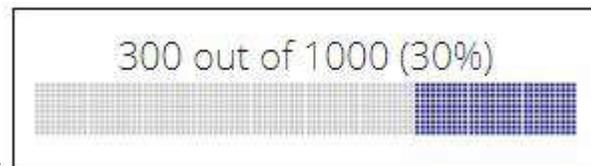
- o Yes
- o No

If yes:

Instructions - part 3

In each question in part 3, two treatment options are described. Some of the features will be the same as before. Assume features not shown are the same for all treatments.

In part 3, you will see three new features:

1) Time for drug to leave your system after stopping treatment

The time that the drug takes to leave your system. Can be either **0** months, **1** month or **3** months.

2) Chance of problems with pregnancy if taken during conception

Example:

The grid of dots represents **1000** women who took the treatment during conception and/or pregnancy, and blue represents women who experienced **problems** with pregnancy.

Problems could include low birth rate, premature birth or miscarriage.

3) Safe to breastfeed

Whether it is safe to breastfeed a child when the drug is present in your system.

Your task

Again, you should imagine that you can only choose between two treatments. Some existing DMTs can't be taken if trying to conceive/pregnant, but imagine neither of the treatment options shown is.

We realise your preferences may change over time, and you may wish to choose different treatments at different time points. For example, if you were trying to conceive, the chance of a safe pregnancy might be more important in your choice of treatment than if you weren't trying to conceive.

Due to this, we'd like you to imagine making your choice at three time points.

(1) Imagine you are making your choice **now.**
(2) Imagine making your choice when you and your partner are **trying to conceive.**
(3) Imagine making your choice when you are **pregnant**.

In each case, choose which out of treatment A and treatment B you prefer, and whether you would prefer your choice over no treatment.

One treatment will be better for some features and one treatment will be better for other features. You should choose the treatment which, on balance, you prefer.

We are interested in your own personal views. There are no right or wrong answers.

There are **FIVE** questions in this section.

REPRODUCTION RELATED DCE QUESTIONS – SEE FIGURE 1 AND FIGURE 2 FOR EXAMPLES

Final part

In this final part, we will ask you a mixture of questions about what you would prefer in an imaginary situation. They are not related to MS or treatment choices. There are no right or wrong answers.

Imagine you can choose between receiving a gift of **£45 today** or **£70** in **one year**. Which would you prefer?

o £45
o £70

Imagine you can choose between receiving a gift of **£50 today** or **£70** in **one year**. Which would you prefer?

o £50
o £70

Imagine you can choose between receiving a gift of **£55 today** or **£70** in **one year**. Which would you prefer?

o £55
o £70

Imagine you can choose between receiving a gift of **£60 today** or **£70** in **one year**. Which would you prefer?

o £60
o £70

Imagine you can choose between receiving a gift of **£65 today** or **£70** in **one year**. Which would you prefer?

o £65
o £70

Imagine you can choose between receiving a gift of **£45** in **one year** or **£70** in **two years**. Which would you prefer?

o £45
o £70

Imagine you can choose between receiving a gift of **£50** in **one year** or **£70** in **two years**. Which would you prefer?

o £50
o £70

Imagine you can choose between receiving a gift of **£55** in **one year** or **£70** in **two years**. Which would you prefer?

o £55
o £70

Imagine you can choose between receiving a gift of **£60** in **one year** or **£70** in **two years**. Which would you prefer?

o £60
o £70

Imagine you can choose between receiving a gift of **£65** in **one year** or **£70** in **two years**. Which would you prefer?

o £65
o £70

How do you see yourself: are you generally a person who is fully prepared to take risks or do you try to avoid taking risks? Please tick a box on the scale, where the value 0 means: 'not at all willing to take risks' and the value 10 means: `very willing to take risks'.

Thank you!

Thank you very much for your help in completing this survey.

- I am happy to be contacted again about follow-up studies to this research.